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RUNNING TITLE: EVALUATING DECISION MAKING CAPACITY

Evaluating Decision Making Capacity: Challenges faced by Clinicians in Switzerland

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Abstract

The study identified factors that make evaluation of decision-making capacity (DMC) difficult for clinicians in their daily work. Semi-structured interviews were carried out with 24 healthcare professionals from Switzerland and were thematically analyzed. Challenges they faced when evaluating DMC stemmed from three main concerns: patient characteristics that impede DMC evaluation; differing opinions and consequences of DMC evaluation; and familial and legal situations that complicate such evaluations. Physicians must be adequately trained to evaluate DMC as it is closely related to basic ethical principles of respect for patients' autonomy and beneficence. Extensive training on DMC evaluation and the legal concept of capacity should be part of pre- and post- graduate education.

Keywords

Decision making capacity; autonomy; capacity evaluation; qualitative study; Switzerland

Introduction

Decision-making capacity (DMC) is an important concept in patient-oriented medicine, both from an ethical and a legal perspective (Beauchamp & Childress, 2009; Buchanan & Dan, 1989). It is a prerequisite to exercise one's right to self-determination, and those deemed to have DMC can act and decide autonomously. In the medical context, every person should have the opportunity to make autonomous choices about his or her medical treatment after being informed of all relevant information necessary for the decision (Checkland, 2001). To perform medical procedures, a valid consent requires the free and informed decision of a competent patient (Buchanan & Dan, 1989; Checkland, 2001). DMC serves a gatekeeping function in health care and helps to distinguish persons whose decisions should be solicited or accepted from those whose decisions should not be indiscriminately followed (Aebi-Müller, 2014; Ganzini, Volicer, Nelson, Fox, & Derse, 2005). However, the concept of DMC has been called into question by Article 12 of the UN Convention on the Rights of Persons with Disabilities, which illustrates the need to support individuals in exercising their legal capacity (Flynn & Arstein-Kerslake, 2014).

When there is doubt about a patient's DMC, physicians have both a legal and a moral obligation to evaluate their capacity (Berghmans, 2001). In most cases, this evaluation is an implicit part of the interaction between the physician and patient (Appelbaum & Grisso, 1988; Hermann, Trachsel, Mitchell, & Biller-Andorno, 2014). There might be circumstances when the physician may doubt a patient's DMC, and an explicit evaluation becomes necessary. There are several tools for the evaluation of DMC (Bean, Nishisato, Rector, & Glancy, 1994; Grisso, Appelbaum, & Hill-Fotouhi, 1997; Lamont, Jeon, & Chiarella, 2013).

Many scholars and practitioners in the field of capacity evaluation (Berghmans, 2001; Hermann et al., 2014; Sjostrand et al., 2015; Trachsel, Hermann, & Biller-Andorno, 2015) agree on the following four criteria to evaluate DMC (Appelbaum & Grisso, 1988): capacity to make and express a choice; capacity to understand relevant information; capacity to evaluate the character of the situation and possible consequences; and capacity to handle information rationally. However, these criteria are not uncontested: inter alia have been criticized for being too cognitively oriented and not sufficiently accounting for emotions and values (Charland, 1998; Hermann, Trachsel, & Biller-

Andorno, in-press; Hermann, Trachsel, Elger, & Biller-Andorno, 2016). It is agreed that DMC is specific to *a* task (Buchanan & Dan, 1989). Therefore, if a person is evaluated as incapable of a specific task, a person should not be deemed incompetent in terms of every sphere of his or her life (Beauchamp & Childress, 2009). In addition, some authors forward a risk-related standard of capacity (Beauchamp & Childress, 2009; Buchanan & Dan, 1989; Ganzini et al., 2005). They highlight that competence to make a choice is relative to the consequences of the decision, and the required cognitive abilities may vary depending on the severity of a decision's possible outcome (Wilks, 1997). Furthermore, complexity of a decision can be a factor that places increased demands on a patient's DMC (Buchanan & Dan, 1989; den Hartogh, 2016).

There is a plethora of studies carried out on DMC, specifically in questions such as capacity to consent for research and use of a proxy decision maker (Karlawish et al., 2013; Kim et al., 2011; Kim et al., 2013). However, few studies are available investigating healthcare practitioners' knowledge of and attitudes towards DMC and the implementation of theoretical concepts in their daily work (Lamont et al., 2013). These studies have shown that misunderstandings concerning operationalization of DMC, knowledge gaps, and discrepancies between attitudes and behaviors are common among healthcare professionals. Moreover, studies have underscored challenges of evaluating DMC in practice in light of patients' cognitive conditions as well as their disease profile (Escandon, Al-Hammadi, & Galvin, 2010; Macleod, 2006; McKeith et al., 2005). Fluctuating capacity raises an additional concern for the evaluating clinician as they may have to make a new evaluation each time there is any change (Martel et al., 2018; Trachsel et al., 2015). Other challenging patient characteristics include addiction disorders, most frequently alcoholism (Restifo, 2013), and treatment refusal (Singelenberg, 1990). In light of the limited evidence available, Seyfried and colleagues (2013) pointed out that future works should seek to help identify and define contextual factors that impede DMC assessments. Our study seeks to address this research gap by using qualitative interview data to identify factors that make evaluation of DMC difficult for clinicians in their daily work.

Methods

This work is based on 24 interviews with healthcare professionals in Switzerland. The interviews used in this analysis were conducted in the framework of a nationally funded study of which the goal was to evaluate a new DMC tool developed by Biller-Andorno, Hermann, and Trachsel. The study participants took part in a 2-hour training session on the concept and evaluation of DMC. This was followed by a 4-month trial of the tool in clinical practice and subsequently, a 1-hour face-to-face interview on their experiences using the tool. Participation was rewarded with six Swiss Institute of Medical Education approved credits for attending the training session.

Sample

A purposive sampling was used to recruit healthcare practitioners for the DMC training session. These participants were invited based on being regularly confronted with doubtful DMC cases including those at the end of life. Participants were recruited via health-institutions within German-speaking Switzerland. A total of 84 healthcare professionals took part in the training session on DMC. They formed the sample for the interview part of the study and 24 of these training participants agreed to be interviewed (response rate of 28.6%). The final interview participants included nurses, physicians, and one psychologist (Table 1).

[Add TABLE 1 HERE]

Data collection

The interviews were conducted in Swiss-German or German by one of the co-authors (HH), who is a trained psychologist and holds a PhD in medical ethics and law. These interviews were completed between April to November 2016. An interview schedule was constructed by the research team (HH, MT, BE) with the evaluation of the tool as the main aim. Besides the questions related to the evaluation (e.g. How did you find the UUKit? For how many cases were you able to use the UUKit in the last months? Could you describe a case for which UUKit was helpful? What are the elements of the UUkit that were particularly helpful / less helpful and why? How they find the capacity decision making process in UUKit) during the interview, the participants were asked about their practice, difficulties, and experience with DMC, difficult cases that they have experienced as well

as documentation of DMC in their normal practice and those related to difficult cases. The interviews were semi-structured and prompting questions were posed based on the participants' responses (e.g., when UUKit's use was or was not successful). The interviews took place in-person at interviewees' offices in the hospital or GP practice, and no other person except for the interviewer and the interviewee was present. The interviews lasted between 22 and 70 minutes (mean 45 minutes).

Data Analysis

The interviews were audio recorded and transcribed verbatim by the first author (LI) and other collaborators. LI is a native German and Swiss-German speaker. She checked the interviews against the audio-recordings to ensure accuracy of transcriptions. Although some of the interviews were conducted in Swiss-German, they were transcribed directly into written German. This is common practice because the former is a dialect and written materials appear in German. Before beginning the analysis, the authors decided to only include information that was not directly related to the new DMC tool developed. The analysis was done by two authors (LI and TW) who initially read the interviews to familiarize themselves with the data and to get an idea of its content. The data were analyzed using semantic thematic analysis as the qualitative approach (Braun & Clarke, 2006) in order to identify challenges that the study participants deemed important. This analysis was done inductively, without pre-determined categories. In a first step, they coded transcripts using the program MAXQDA12. Codes expressing a similar meaning were placed into three major categories: (i) indications for DMC evaluations; (ii) how DMC evaluations had been conducted; and (iii) challenges clinicians had faced when evaluating DMC. Due to the richness of data, they decided to only do a further in-depth analysis on the third category, challenges faced by clinicians. All initial codes sorted in this category and any other related codes were re-analyzed inductively by the first author, looking for factors that cause challenges in the daily practice of these clinicians. The codes were put together into three main themes after discussion with TW who also read and independently coded five transcripts. These main themes are presented below in the results section using quotes from the interviews. The quotes have been translated from German to English and checked for language consistencies by co-authors, TW and BE, who are fluent in German and English. Additional information have been added to the quote to improve comprehension where necessary using [ ]. To improve interpretations of the data, five full-

transcripts were read independently by the three co-authors (HH, MT, BE) and the final findings in the present paper were agreed upon by all authors. During data analysis, the authors found that no new themes and sub-themes emerged after coding approximately one-third of the interviews; however, we coded all interviewed data to ensure that all collected data were used.

Results

The challenges faced by the study participants in evaluating DMC were often related to difficult cases that they faced. A total of 32 cases were discussed by 20 of the 24 study participants. These cases included patient characteristics that made evaluation necessary such as older persons with dementia or the presence of mental health conditions that mean being alone is a risk despite their wishes to go home. Difficult cases also comprised divergent opinions between patients and physicians and between family members and physicians concerning treatment and DMC, and cases where they were asked to evaluate capacity for legal reasons. Since our goal was to explore challenges to DMC, we not only used the cases discussed but also general statements healthcare professionals made during the interviews.

Patient Characteristics Impeding Evaluation of DMC

Several patient characteristics made it difficult for the participating healthcare professionals to conclude whether a patient had (sufficient) decision making capacity or not. These characteristics were mostly related to the patient's medical condition, such as presence of dementia, diseases that may result in cognitive fluctuations, and psychiatric illnesses, all of which posed the question of whether they affect DMC to the extent that the patient is deemed legally incapacitated.

Cases reported often described patients with early-stage dementia or with mild cognitive impairment where it was questionable whether he or she had the capacity to make a specific decision. In these cases, evaluations were necessary to assess a person's ability to participate in their treatment decisions. However, participants also reported that some of the patients with dementia refused cooperation and therefore impeded the evaluation (Q2, Table 2). Only in cases where dementia was advanced did physicians seem to think that there was no need for evaluation because the patient clearly lacked capacity (Q1, Table 2).

[ADD TABLE 2 HERE]

For several physicians, fluctuations in patients' cognitive abilities meant that they could not confidently conclude about the presence or absence of DMC. A physician discussed hurdles she had encountered when assessing DMC in patients with cognitive fluctuation and pointed to (possibly treatable) delirium as a potential reason. Physicians said they worried about the fact that in patients where cognitive abilities fluctuate from one instant to the next, evaluation outcomes depend on the exact moment of the evaluation (Q3, Table 2). Similarly, a nurse illustrated difficulties in taking care of a patient suffering from cancer who presented constantly fluctuating cognitive capabilities (Q4, Table 2).

Several participants reported challenges due to complex medical situations. Medical situations were deemed complex if a patient suffered from multiple diseases or diseases that require intense and specialized treatment. In these cases, it was perceived as difficult to communicate the consequences of medical interventions, even to patients with only slight cognitive impairments. For instance, a general practitioner pointed out a case of an older woman (from another country) suffering from breast cancer and early stage dementia who did not understand the consequences and recommendations of a possible treatment (Q5, Table 2).

Often, the participants discussed challenging situations related to psychiatric diseases (alcohol and drug abuse, schizophrenia, depression) (Q6, Table 2). A physician described the situation of a woman who was suffering from several substance abuse disorders and had been hospitalized eight times in one year (Q7, Table 2).

Differing Opinions and Consequences of DMC Evaluation

Some physicians reported challenges when patients make decisions that are contrary to their medical advice, that is, patient refusal to follow medical advice or treatment. This was a common thread in many of the difficult situations. One physician stated; "It would be more difficult if I thought that it wasn't a good idea, if I couldn't accept the patient's wish [to go home despite a high risk of falling]" (P1, internal Medicine/Geriatrics, Female). Participants felt that patients in these cases are likely to harm themselves, as specified in the example of an 87-year-old patient who suffered from a metastasized carcinoma of the prostate and decided to take control of his death by starving himself

(Q8, Table 3). Another physician spoke about a case in which the patient did not want to amputate his leg, however, without amputation he might have died (Q9, Table 3).

[ADD TABLE 3 HERE]

Additionally, while a physician felt that the patient had DMC, the patient was deemed to be incapable by the physicians' colleague, a psychiatrist, which made the situation even more difficult: "I found [this case] quite challenging, because – he was actually deemed to be incapable [by a psychiatrist]" (P12, Internal Medicine, Female). In another case, the physician's decision depended on whether it would put a financial burden on the patients' family; "according to the law we can force her into involuntary commitment in a care home, which however would be a serious financial obstacle for the family as it costs CHF 6'000 per month. That's difficult" (P18, Internal Medicine, Male). Finally, participants were also anxious when they had different opinions about the patient from those of the relatives (Q10, Table 3). Some of the relatives even made physicians change their decisions (Q11, Table 3).

Familial and Legal Situations Affecting Evaluation of DMC

The evaluation of DMC was also influenced by third parties, that is, family members and legal representatives. Many physicians discussed issues related to relatives: they can add important information about the patient's history for the DMC evaluation, and their absence can be a challenge (Q12, Table 4).

Several physicians reported challenges when the evaluation was done in the context of legal issues. In some cases, relatives or lawyers had requested DMC evaluations to assess patients' DMC to sell or give away their home (Q13, Table 4). In another case, a physician was asked to assess historical DMC for a legal decision made in the past (Q14, Table 4). Finally, a physician stated that sometimes it is not clear whether they should be making the DMC appraisals in these situations (Q15, Table 4).

Discussion

This study identified factors that - from the perspective of treating physicians and other medical professionals - make DMC evaluation difficult in healthcare professionals' daily practice in Switzerland. To provide practice-oriented training on DMC and its concepts, it is important to

understand the challenges that healthcare providers encounter in their daily work. The study findings are thus valuable considering the scarce existing information (Hermann et al., 2014; Jackson & Warner, 2002; Lamont et al., 2013; Seyfried et al., 2013) on application and implementation of DMC in clinicians' daily practice.

As evident in available literature (Karlawish et al., 2013; Kim et al., 2011; Martel et al., 2018; Restifo, 2013), our results provide further evidence on the challenges associated with patient characteristics that make DMC evaluations particularly difficult. The most frequent characteristics were mild cognitive impairment or the beginning of dementia, fluctuating psychiatric symptoms including symptoms of delirium caused by organic disease, and addiction disorders. Healthcare professionals seemed more at ease when incapacity was general and persisting, e.g. in the case of advanced dementia during which capacity decline is clearly evident (Huthwaite et al., 2006). Cognitive fluctuations can occur with a number of diseases and conditions such as delirium, Alzheimers' disease, and Lewy-Body dementia (Escandon et al., 2010; Macleod, 2006; McKeith et al., 2005). For example, a recent study in the emergency setting found that intoxicated patients do not possess capacity to provide informed consent (Martel et al., 2018). This study revealed that although patients completed the questionnaire consenting their participating in a study, many did not remember having done so when they were sober. Hence, when patients present themselves in situations where their capacity may vary from one time point to another, it becomes necessary to carry out re-evaluations to detect the patient's best possible cognitive state (Appelbaum & Grisso, 1988). However, this is a considerable addition to the clinical routine because re-evaluations are time-consuming and time is generally in short supply in clinical practice.

Our study also highlights that being the physician tasked with such evaluation was also a difficult position to find oneself in because of the potential for conflicts. They felt uncertain when dealing with disagreements about DMC evaluations and doubted their own evaluation when the opinions of colleagues or relatives differed from their own. This was particularly true in cases for which the evaluation took place in the context of a lawsuit where relatives claimed that the patient was not competent to make financial decisions. These difficult situations and related cases also reveal that DMC evaluation was affected by potentially solvable communication problems. Communication

issues seem to also arise in complex medical situations where prognosis is communicated by the expert (e.g. oncologist) as a relative risk reduction, which is more difficult to understand when accompanied with linguistic barriers. In these situations, communication could be clearly mediated by adequate translation, explanation of absolute risks, and patient- or layperson- adapted presentation of statistical information. It must be noted that understanding the language is a pre-requisite for making any assessment regarding a patient's ability to decipher what is communicated and their coming to a choice. Language has been shown to be a critical barrier to provision of healthcare for immigrants (Bischoff & Denhaerynck, 2010; Drewniak, Krones, Sauer, & Wild, 2016; Hudelson, Dao, Perneger, & Durieux-Paillard, 2014), and there is no evidence to believe otherwise in the case of DMC assessments. Thus, the importance of having a common language, and when that is not possible, a sufficient means of translation, is critical to providing care to patients who do not come from the same language regions as the healthcare provider.

Study findings reveal that treatment refusals by patients resulted in challenging situations, which indicates that training should specifically address ways to evaluate DMC in such situations. The examples presented by our participants demonstrate that refusals imply two major difficulties for physicians where training is crucial. First, a patient decision which does not follow physician advice is perceived as irrational and is thus interpreted as a sign of lacking DMC. Second, healthcare professionals feel responsible to protect patients against their own "bad" decisions as demonstrated by the report of the respondent (a psychologist) who had been approached by physicians to evaluate capacity in an 87 year-old patient who wanted to starve himself (see Q8). Healthcare professionals play an important role in respecting patient's decision making rights. Previous studies have shown that a physician's decision about a patient's DMC might be influenced by his or her own values (Hermann, Trachsel, & Biller-Andorno, 2015). It is not surprising to find that for physicians, it is easier to confirm DMC for a decision if it is aligned with their own values and expectations or the common goals of medicine. However, there is the need to understand that patients might have different priorities and thus, specific training should help nurture awareness and sensibilities towards reducing such biases. For example, training should address their role in terms of favoring respect for autonomy which can be in conflict with physicians' perception of responsibility for harm (at least in the eyes of

the physician). Evaluating a patient as competent or not can have significant consequences for the patients. Moreover, in situations where families' financial situation is at risk because of DMC evaluation or there is risk of harm when frail patients wish to return home, physicians must recognize and respect different preferences in terms of acceptance of risk. Patients might value living at home to the extent that they accept higher risks of harm. Teaching healthcare professionals about risk-relative standards for DMC evaluations is important in this context (Beauchamp & Childress, 2009; Buchanan & Dan, 1989; Ganzini et al., 2005).

The study found that healthcare professionals did not like to be in situations where relatives disagreed with their DMC evaluations. The important role of the relatives has been recognized in the literature (Appelbaum & Grisso, 1988; Hardart & Truog, 2003; Itzhaki, Hildesheimer, Barnoy, & Katz, 2016). On one hand, they can provide information that is relevant to the evaluation and helps the healthcare providers to ascertain a more accurate picture of the patient's condition. On the other hand, relatives may not be objective observers, due to emotions caused by their closeness to the patient or conflicts of interests and thus unduly influence physicians' opinion. Healthcare professionals therefore must be taught to carefully distinguish between relevant information and information biased by personal interests (Hermann et al., 2014). Also related was the issue of possible allegations of financial abuse by relatives and relatives viewing older persons at risk of financial exploitation, resulting in their demands for DMC assessment. However, such demands were more in the legal context than medical, and those study participants who faced these situations found themselves in an unclear position. A possible reason could be their lacking knowledge in the intersection of medicine and law (Parker, Willmott, White, Williams, & Cartwright, 2015; Persad, Elder, Sedig, Flores, & Emanuel, 2008).

Recommendations

In light of the study findings, the following recommendations seem crucial to improve the current standard of practice. First, since factors related to a patient's health condition (e.g. dementia) will persist or even increase in frequency in the future given the demographic changes of an ageing society, it is important that healthcare professionals have the specialized knowledge to navigate these challenging medical situations and appropriately assess DMC. Second, situations where patients

present complex medical situations (e.g. dementia combined with patients' desire to return home, lack of social resources and support) require clear communication. Healthcare professionals should thus receive appropriate training to understand and respect different values and needs of their patients (including those from different cultural backgrounds), ensuring the best outcome defined by patient preferences. Furthermore, imbibing them with skills to improve their ability to communicate information to lay persons in simple and understandable terms is also critical. Third, DMC evaluations in the context of lawsuits leave much space for potential difficulties. Physicians need to be aware of ethical challenges related to double roles as treating physician and expert. They should be encouraged to consider when it is ethically appropriate to accept or reject a mandate of an expert or when it is necessary to involve professional ethics consultation or receive second opinions from other colleagues. Also, healthcare professionals need more knowledge on legal topics and regulation of competencies. These should be integrated in pre- as well as postgraduate training. It could be easily done in practice by hospitals and universities through workshops on specific legal topics with case examples. The workshops should be updated with newer and more nuanced examples over time to sharpen the core skills of healthcare professionals. Finally, an interdisciplinary approach to promote better communication between healthcare and legal professionals is necessary to protect patient rights and to attain the highest quality of DMC evaluations.

Limitations and further research

The qualitative study design means that we did not interview a representative sample of all healthcare professionals, and thus the findings cannot be generalized neither to any other situation nor contexts. However, the fact that healthcare professionals from various backgrounds and experiences reported similar cases indicates that we identified relevant perceived difficulties related to DMC evaluations. With regard to the small number of conducted interviews, it is important to acknowledge that we could not possibly detect all types of difficulties related to DMC evaluations. As the main focus of the interviews was to collect feedback on a new tool developed to evaluate DMC in patients, the question about difficult cases was not explicitly raised in all interviews. Furthermore, the depth in which a case example was described and discussed varied between interviews. As information about the newly developed DMC tool evaluation was excluded in this analysis, it could be that we missed

some general difficulties concerning DMC evaluation that those parts of the data may have contained. It is crucial to notice that all participants took part in a training session on a new tool to evaluate DMC where conceptual aspects of DMC were discussed, and thus it can be assumed that our examined sample of health care professionals is more familiar with the concept of DMC. However, because those that had already received some training report difficulties, it is very likely that challenges will be even higher among healthcare professionals unfamiliar with DMC evaluations, although the latter might not notice when their evaluations are influenced by lack of knowledge or misconceptions about DMC. Further research to detect difficulties should be encouraged in order to increase quality and appropriateness of DMC evaluations in line with respect for patient rights.

Conclusion

In clinical practice, healthcare professionals must receive adequate training to evaluate DMC as it is closely related to basic ethical principles such as respect for patient autonomy and beneficence. Theoretical concepts are extensively discussed in the literature, but there appears to be a dearth of published insights on actual clinical implementation of these concepts. Our study is important as it shows that healthcare professionals struggle with a number of typical situations where evaluation of DMC is a complex process, which can be influenced by many factors relating to the various stakeholders and legal issues. More extensive training on DMC evaluation and the legal concept of capacity should be urgently provided in pre- and post- graduate education, and treating physicians should be trained regarding when to delegate evaluation to independent experts or to seek further ethical advice and second opinions.

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References

Aebi-Müller, R. (2014). Der urteilsunfähige Patient- eine zivilrechtliche Auslegeordnung. *Jusletter*.

Appelbaum, P. S., & Grisso, T. (1988). Assessing patients' capacities to consent to treatment. *N Engl J Med, 319*(25), 1635-1638. doi: 10.1056/nejm198812223192504

Bean, G., Nishisato, S., Rector, N. A., & Glancy, G. (1994). The psychometric properties of the Competency Interview Schedule. *Can J Psychiatry, 39*(8), 368-376.

Beauchamp, T., & Childress, J. (2009). *Principles of Biomedical Ethics*: Oxford University Press.

Berghmans, R. L. (2001). Capacity and consent. *Current Opinion in Psychiatry, 14*(5), 491-499.

Bischoff, A., & Denhaerynck, K. (2010). What do language barriers cost? An exploratory study among asylum seekers in Switzerland. *BMC Health Services Research, 10*(1), 248. doi: 10.1186/1472-6963-10-248

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Buchanan, A., & Dan, B. (1989). *Deciding for others, The Ethics of Surroggate Decision Making*: Cambridge University Press.

Charland, L. C. (1998). Is Mr. Spock mentally competent? Competence to consent and emotion. *Philosophy, Psychiatry, & Psychology, 5*(1), 67-81.

Checkland, D. (2001). On risk and decisional capacity. *J Med Philos, 26*(1), 35-59. doi: 10.1076/jmep.26.7.35.9168

den Hartogh, G. (2016). Do we need a threshold conception of competence? *Med Health Care Philos, 19*(1), 71-83. doi: 10.1007/s11019-015-9646-5

Drewniak, D., Krones, T., Sauer, C., & Wild, V. (2016). The influence of patients' immigration background and residence permit status on treatment decisions in health care. Results of a factorial survey among general practitioners in Switzerland. *Soc Sci Med, 161*, 64-73. doi: 10.1016/j.socscimed.2016.05.039

Escandon, A., Al-Hammadi, N., & Galvin, J. E. (2010). Effect of cognitive fluctuation on neuropsychological performance in aging and dementia. *Neurology, 74*(3), 210-217. doi: 10.1212/WNL.0b013e3181ca017d

Flynn, E., & Arstein-Kerslake, A. (2014). Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity. *International Journal of Law in Context, 10*(1).

Ganzini, L., Volicer, L., Nelson, W. A., Fox, E., & Derse, A. R. (2005). Ten myths about decision-making capacity. *J Am Med Dir Assoc, 6*(3 Suppl), S100-104. doi: 10.1016/j.jamda.2005.03.021

Grisso, T., Appelbaum, P. S., & Hill-Fotouhi, C. (1997). The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. *Psychiatr Serv, 48*(11), 1415-1419. doi: 10.1176/ps.48.11.1415

Hardart, G. E., & Truog, R. D. (2003). Attitudes and preferences of intensivists regarding the role of family interests in medical decision making for incompetent patients*. *Critical Care Medicine, 31*(7), 1895-1900. doi: 10.1097/01.ccm.0000084805.15352.01

Hermann, H., Trachsel, M., & Biller-Andorno, N. (2015). Physicians' personal values in determining medical decision-making capacity: a survey study. *J Med Ethics, 41*(9), 739-744. doi: 10.1136/medethics-2014-102263

Hermann, H., Trachsel, M., & Biller-Andorno, N. (in-press). Accounting for intuition in decision-making capacity: Rethinking the reasoning standard? . *Philosophy, Psychiatry, & Psychology.*

Hermann, H., Trachsel, M., Elger, B. S., & Biller-Andorno, N. (2016). Emotion and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments. *Front Psychol, 7*, 765. doi: 10.3389/fpsyg.2016.00765

Hermann, H., Trachsel, M., Mitchell, C., & Biller-Andorno, N. (2014). Medical decision-making capacity: knowledge, attitudes, and assessment practices of physicians in Switzerland. *Swiss Med Wkly, 144*, w14039. doi: 10.4414/smw.2014.14039

Hudelson, P., Dao, M. D., Perneger, T., & Durieux-Paillard, S. (2014). A "Migrant Friendly Hospital" Initiative in Geneva, Switzerland: Evaluation of the Effects on Staff Knowledge and Practices. *PLOS ONE, 9*(9). doi: ARTN e106758 10.1371/journal.pone.0106758

Huthwaite, J. S., Martin, R. C., Griffith, H. R., Anderson, B., Harrell, L. E., & Marson, D. C. (2006). Declining medical decision-making capacity in mild AD: a two-year longitudinal study. *Behav Sci Law, 24*(4), 453-463. doi: 10.1002/bsl.701

Itzhaki, M., Hildesheimer, G., Barnoy, S., & Katz, M. (2016). Family involvement in medical decision-making: Perceptions of nursing and psychology students. *Nurse Education Today, 40*, 181-187. doi: 10.1016/j.nedt.2016.03.002

Jackson, E., & Warner, J. (2002). How much do doctors know about consent and capacity? *J R Soc Med, 95*(12), 601-603.

Karlawish, J., Cary, M., Moelter, S. T., Siderowf, A., Sullo, E., Xie, S., & Weintraub, D. (2013). Cognitive impairment and PD patients' capacity to consent to research. *Neurology, 81*(9), 801-807. doi: 10.1212/WNL.0b013e3182a05ba5

Kim, S. Y. H., Karlawish, J., Kim, H. M., Wall, I. F., Bozoki, A., & Appelbaum, P. S. (2011). Preservation of the Capacity to Appoint a Proxy Decision Maker: Implications for Dementia Research. *Archives of General Psychiatry, 68*(2), 214-220. doi: 10.1001/archgenpsychiatry.2010.191

Kim, S. Y. H., Kim, H. M., Ryan, K. A., Appelbaum, P. S., Knopman, D. S., Damschroder, L., & De Vries, R. (2013). How Important Is 'Accuracy' of Surrogate Decision-Making for Research Participation? *PLOS ONE, 8*(1), e54790. doi: 10.1371/journal.pone.0054790

Lamont, S., Jeon, Y. H., & Chiarella, M. (2013). Health-care professionals' knowledge, attitudes and behaviours relating to patient capacity to consent to treatment: an integrative review. *Nurs Ethics, 20*(6), 684-707. doi: 10.1177/0969733012473011

Macleod, A. D. (2006). Delirium: the clinical concept. *Palliat Support Care, 4*(3), 305-312.

Martel, M. L., Klein, L. R., Miner, J. R., Cole, J. B., Nystrom, P. C., Holm, K. M., & Biros, M. H. (2018). A brief assessment of capacity to consent instrument in acutely intoxicated emergency department patients. *The American Journal of Emergency Medicine, 36*(1), 18-23. doi: https://doi.org/10.1016/j.ajem.2017.06.043

McKeith, I. G., Dickson, D. W., Lowe, J., Emre, M., O'Brien, J. T., Feldman, H., . . . Yamada, M. (2005). Diagnosis and management of dementia with Lewy bodies: third report of the DLB Consortium. *Neurology, 65*(12), 1863-1872. doi: 10.1212/01.wnl.0000187889.17253.b1

Parker, M., Willmott, L., White, B., Williams, G., & Cartwright, C. (2015). Medical education and law: withholding/withdrawing treatment from adults without capacity. *Internal Medicine Journal, 45*(6), 634-640. doi: 10.1111/imj.12759

Persad, G. C., Elder, L., Sedig, L., Flores, L., & Emanuel, E. J. (2008). The current state of medical school education in bioethics, health law, and health economics. *J Law Med Ethics, 36*(1), 89-94, 84. doi: 10.1111/j.1748-720X.2008.00240.x

Restifo, S. (2013). A review of the concepts, terminologies and dilemmas in the assessment of decisional capacity: a focus on alcoholism. *Australas Psychiatry, 21*(6), 537-540. doi: 10.1177/1039856213497812

Seyfried, L., Ryan, K. A., & Kim, S. Y. (2013). Assessment of decision-making capacity: views and experiences of consultation psychiatrists. *Psychosomatics, 54*(2), 115-123. doi: 10.1016/j.psym.2012.08.001

Singelenberg, R. (1990). The blood transfusion taboo of Jehovah's Witnesses: origin, development and function of a controversial doctrine. *Soc Sci Med, 31*(4), 515-523.

Sjostrand, M., Karlsson, P., Sandman, L., Helgesson, G., Eriksson, S., & Juth, N. (2015). Conceptions of decision-making capacity in psychiatry: interviews with Swedish psychiatrists. *BMC Med Ethics, 16*, 34. doi: 10.1186/s12910-015-0026-8

Trachsel, M., Hermann, H., & Biller-Andorno, N. (2015). Cognitive fluctuations as a challenge for the assessment of decision-making capacity in patients with dementia. *Am J Alzheimers Dis Other Demen, 30*(4), 360-363. doi: 10.1177/1533317514539377

Wilks, I. (1997). The debate over risk-related standards of competence. *Bioethics, 11*(5), 413-426.

Table 1: Sample information (N=24)

	n	%
Gender		
Man	12	50.0
Women	12	50.0
Profession		
Physician	18	75.0
Psychologist	1	4.2
Nurse	5	20.8
Training (only Physicians)		
Internal Medicine	7	38.8
Internal Medicine/Geriatric	3	16.6
Dermatology	1	5.5
Radio-oncology	1	5.5
Psychiatry	6	33.3
Years of experience		
<10 years	7	29.2
>10 years	17	70.8

Table 2: Patient characteristics making DMC evaluations difficult

Quote	Patient Characteristics	Participant's voice
Q1	Patient refuses DMC - dementia present	He went through a severe pneumonia, comes from the XX-hospital (…) he always wanted to go home. Now he is here [in the geriatrics unit] and still wants to go home, and he says that he's staying until Friday. From a clinical perspective, he appears cognitively limited. An evaluation is not possible as he refuses it. Dementia is suspected. (P6, Internal Medicine/Geriatrics, Male)
Q2	Presence of dementia	It's relatively common in general practice [that patients have] minor symptoms of dementia. In the case of more serious types of dementia it is clear somehow (…) it's evident that the person does not have DMC anymore. (P7, Internal Medicine, Male)
Q3	Cognitive fluctuations	(…) partly it is, you see a patient on day A and he was just like that, and if you see him on day B you think: Hm. Maybe you would have even made a different evaluation. (…) This really is kind of a current snapshot and it can change by all means. Especially with our delirious patients. (P9, Radio-oncology, female)
Q4	Cognitive fluctuations	I just had such a situation last week, when he [a patient] told me "yes, that's fine, we do it like this" and two hours later, something happened, maybe a metastasis in the brain (…) and he changed his mind and the situation was completely different. And then he wants completely different procedures, than the ones we planned and we agreed on. (P22, Nurse, Male)
Q5	Patient illness compounded with communication barrier	[the oncologist] mentioned a recurrence risk reduction [of the breast cancer] of 30 percent. It was difficult to tell her what this means since she neither fully understood nor wanted to understand (…) The oncologist's clear recommendation was to undergo chemotherapy. However, the probability of real improvement is unclear - that was difficult to say. She went to see an oncologist afterwards, but it didn't clarify the situation, in part also due to additional language problems. She speaks (another language). (P7, Internal Medicine, Male)
Q6	Mental health status	Patients suffering from psychosis are difficult, those who count elephants up there or hear voices, but as long as others don't feel threatened and are not (self-) endangered, it is no - this is usually no issue [to doubt their DMC]. But - but if they fall into [states of] delusions … the critical perception ceases sometimes. (P10, Internal Medicine, Male)
Q7	Inability to care for self	[the female patient suffers from] chronic pain and has an addiction problem to several substances (…). (…) She's not willing to admit that she can't go home anymore. We face the same situation again and again [Patient was at the hospital eight times this year], so it doesn't work anymore at home. (P18, Internal Medicine, Male)

477

Table 3: Challenges with DMC evaluations when opinions are divergent

Quote	Diverging opinions	Participant's voice
Q8	Patient asserting his right to treatment decision	The physicians wanted to clarify the situation [of an 87-year-old patient suffering from metastasized carcinoma of the prostate who decided to take control of his death by starving himself] and came to him to the palliative care ward [where the participant works]. [The physician wanted me to] check whether it is accurate [that the patient has capacity] or there is need for an intervention. It is a very special request [by the physicians] (P19, Psychologist, Female)
Q9	Patient asserting his right to treatment decision	[He] had a bad infection in his leg, vessels were blocked, he had diabetes and so on, and the surgeons recommended an amputation urgently, otherwise he would die. He refused totally, or, he did not want that under any circumstances (…) and then he had a sepsis and so on, then I went to see him and I said (…) you probably have to die, and he grasped that, but we could try to amputate the leg, and then – he just said no. (P12, Internal Medicine, Female)
Q10	Between family members and physicians	Well it was a patient who uhm came to us too and who wasn't capable of making judgements. But then he changed for the better. And uhm, then the difficulty really was (sighs), yes, basically to show that he is capable of making judgements again (...) [since] his own children questioned [the patient's capacity] and whether this would actually work out [discharge from the hospital]. (P9, Radio-oncologist, Female)
Q11	Between family members and physicians	In my opinion, relatives still play a central role too. They can exert quite some pressure as well, especially in a hospital. They feel slightly offended too if you deem the grandma as not having capacity: She has always made her own decisions, so why shouldn't it work right now. There have been cases in which I caved in and thought afterwards, okay well, they know their grandma. They should bear their share of responsibility." (P2, Psychiatry, Female)

Table 4: Situations that make DMC evaluations difficult

Quote	Situation	Participant's voices
Q12	Lacking information from family to complete medical history	It was very difficult, in her case especially that the husband, who was 30 years younger, left the patient here [at the hospital] (…) And we just had her story but we didn't have a medical history provided by an [independent] third party. In my opinion, it is extremely difficult to evaluate decision making capacity in this case [without third party information, husband being abroad]. (P8, Dermatology, Female)
Q13	(Family members request) for legal decision on capacity	On several occasions, [financial] donations were the problem, or that someone from the family doubted that she [the patient] is capable of making rational judgements because she sold the house at a reduced price or did something else or wanted to do it, and then the relatives stepped in and said that she's not capable of making rational decisions, or respectively, a lawyer wanted to know if this person can be considered competent. (P10, Internal Medicine, Male)
Q14	Legal capacity evaluation in the context of suspected financial abuse	It was a patient suffering from dementia with her son. The patient had already designated a power of attorney [to a different person] and she had accused her son of stealing money. (…) For me, this was a situation in the course of an outpatient consultation. (…) I don't know if she still was capable of making rational decisions at that point in time, but thankfully, I didn't take a position on this, but she somehow made this at home together with a lawyer or a notary. And I just realized that this is a problem, there is a problem. (P5, Internal Medicine/Geriatrics, Female)
Q15	Physician asked to comment on DMC for legal contexts	In the case of complex financial transactions when we are asked as a specialist to comment on the person's capacity (…) you have to check if it's really our task as clinician (…) and if it isn't the job of a legal expert (…) when it's about the signing of the contract. (P6, Internal Medicine/Geriatrics, Male)

479